“Letters in the Time of Covid” : the lived experiences during the pandemic of young adults with disabilities in Cork.

Loretta Sweeney

CARL Research Project
in collaboration with

National Learning Network

CARL
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RESEARCH LINKS
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CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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Declaration:

"Letters in the Time of Covid": the lived experiences during the pandemic of young adults with disabilities in Cork.

Student Number: 113138359 **Student Name:** Loretta Sweeney

I declare that the content of this dissertation is all my own work. Where the work of others has been used to argument my research, it has been referred to accordingly.

Signed: Loretta Sweeney

Date: 30th April 2021

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Chapter 1: Introduction

1.1 Title

"Letters in the Time of Covid" : the lived experiences during the pandemic of young adults with disabilities in Cork

1.2 Introduction to Research

The following research aims to document the lived experiences of the Covid-19 pandemic for a group of young adults with disabilities. All participants are students of the National Learning Network and further explanation is given in the next section. The use of letter writing was conceived as the medium through which the participants could express their feelings and views of the pandemic in real time. It was deemed to be less invasive for students whilst observing ever-changing governmental public health restrictions in regard to social distancing and limiting travel.

1.3 The National Learning Network

The National Learning Network offers training and specialist support to people who may have difficulties gaining employment. The diverse cohort the National Learning Network caters to may include people with disabilities, those with a long term illness or people who are long term unemployed. The National Learning Network is Ireland's largest non-governmental education and training organisation and offers a wide variety of vocational training programmes. The participants in this research are all students of the 'PACES' programme which works with 18-25 year olds to develop their generic work skills as well as their independent living skills. Students are encouraged to work at their own pace as reflected in the course name. Examples of topics covered include 'social skills, IT skills, timekeeping, teamwork, household skills, communication and problem solving. The students also carry out a work placement.

1.3.1 Community Academic Research Links

The Community Academic Research Links (CARL) initiative works with non-profit, voluntary and community organisations, whom they invite to identify areas of research that have a direct impact on communities. CARL cites the promotion of equality, justice and diversity as well as a commitment to addressing issues of poverty and inclusion as a means of creating positive social change. The concept of community based action research is discussed later in this chapter (see 1.7)

1.4 Rationale

1.4.1 Personal Perspective

My work as a healthcare assistant over the last twenty years has brought me in close contact with disability. The concept of disability is indeed diverse and multi-faceted and was demonstrated to me through my work in oncology, psychiatric, geriatric, palliative and rehabilitation units. I believe my experience shows my commitment to professionalism and person-centred values that includes integrity and inclusion as core personal beliefs.

During second year of the Bachelor of Social Work, I volunteered with the Certificate for Contemporary Living (CCL) in University College, Cork. CCL offers education and training for adults with a disability which includes employability and independent living skills similar to the National Learning Network. I saw first-hand the progress of the students in terms of their abilities, knowledge and confidence as the year progressed. I also saw the diversity and individuality of the class and realised the importance of the individual defining their own identity and needs. This experience sparked further interest in the rights of people with disabilities and their place in society.

1.4.2 Social Work Perspective

Social work is broad and diverse in nature as it is informed by a number of different disciplines. Doel (2012) considers this multi-faceted profession and describes the need for social work to draw on such disciplines as 'sociology and psychology'. In a wider structural and organisational context it must engage with concepts such as "Philosophy, politics, economics and the law" (p7). Social work is potentially very well positioned to engage with and advocate for the nuanced concept of disability and the barriers that will be discussed in the next section.

1.5 Background

The concept of disability has evolved in Ireland. For most of the 20th century disability was seen through a more medical lens. Disability was defined in terms of impairment or something that required medical intervention. This view meant disability at best was seen as something to be taken care of and at worst something to be hidden in the many segregated residential settings around the country. Informal and charity/voluntary delivery of care dominated at this time (Dukelow and Considine, 2017). The civil rights movement of the 60's and 70's arguably inspired the move to a more social model of disability that highlighted more societal and organisational structures that excluded people with disabilities. Quin and Redmond (2003) consider this exclusion in terms of barriers, be they attitudinal or physical. More recently a rights based view of disability speaks directly to this exclusion as it places paramount

importance on the inherent dignity of individuals. The United Nations Convention on the Rights of Persons with Disabilities provides a more comprehensive definition of disability:

"*long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* (Art. 1)

Quinn and Degener (2002) state "people with disabilities have a stake in and a claim on society that must be honoured" (p14). The authors elaborate that the "primary responsibility for ensuring respect for the human rights of persons with disabilities rests with States" (p2). The Covid-19 pandemic and resulting lockdown have seen the closure of businesses and the restriction of services.

1.6 Theoretical Perspective

Community based action research is described by Stringer (2007) as seeking "to engage "subjects" as equal and full participants in the research process" (p10). Stringer cites notable characteristics of research namely "democratic…equitable…liberating...life enhancing" (p11). The collaborative nature of 'community based action research' heightens the stakeholders, agency and practitioners' understanding of the perceived issues that can inform solutions or changes in work practices that prove more 'life enhancing'. Bates and Burns (2011) refer to student involvement in community based action research as a "reciprocal aspect of the exchange, whereby all parties benefit from the research process" (p69). The 'parties' namely the participants of the research, the community partner, the researcher and the university can use and build on the data gathered, foster links between all parties and the student is afforded the invaluable opportunity to carry out a research project that has a direct impact on the community.

1.7 Research Aims and Objectives

This research project aims to highlight the experiences of Covid-19 restrictions on the users of the National Learning Network (NLN). The research aims to document the participants' lived experience of the impact these restrictions has had on their access to services, their mental health and potential life plans. This research will contribute to an Art based exhibition. This exhibition hopes to utilise Art and letter writing as a less invasive way of identifying and relating the participants' views on the impact Covid-19 on their lives.

1.7.1 Aims

The overall aim of the research was to identify and document the lived experience of young adults with disabilities in relation to the Covid-19 pandemic and consequent restrictions. Documenting these experiences in real time is hoped to give voice to this demographic thus potentially highlighting the impact on the supports available to them.

1.7.2 Objectives

The aim as stated above would be captured through the medium of letter writing as a less invasive way to collect data according to the community partner, National Learning Network. To encourage engagement with letter writing the agency liaison offered some guiding questions. It was not expected they would be answered verbatim and students were encouraged to write about their individual experience to include whatever issues arose for them.

1.7.3 The Suggested Questions

The participants were given the following questions as a suggestion of themes that they may like to write about.

1. What was the best thing about the lockdown?
2. What was the worst thing about the lockdown?
3. What did you miss the most and why?
4. Did you learn any new skills during this time?
5. If you could change anything about your experience of Covid or the lockdown, what would that be?
6. How will you remember 2020?
7. What helped you the most during this time?
8. What space did you spend the most time in and why?

1.8 Conclusion and Overview of Research Chapters

Chapter one has provided an overview and context to the research in discussing the core elements that have contributed to the process of writing this report. Chapter two ‘Literature Review’ will provide a review of relevant literature to provide a wider context to the issue of disability and Covid-19. Chapter three ‘Methodology’ will outline in more detail the process by which the data was gathered, identified and analysed. Chapter four, ‘Data Analysis and Findings’, will document the findings uncovered during the analysis of the primary data as outlined in chapter 2. Finally Chapter five , ‘Recommendations and

Reflections', will outline the key findings of the research followed by recommendations having considered this data. The author will conclude the research with a reflection on carrying out this research.

Chapter 2: Literature Review

2.1 Introduction

The following literature review aims to provide a wider context to the title of this research-*"Letters in the Time of Covid" : the lived experiences during the pandemic of young adults with disabilities in Cork".* The issue of disability needs to be explored in its historical context, the author asserts, as it may have some bearing on the lived experiences of adults with disabilities in Irish society today. These attitudes therefore may inform the social, political and legislative priority of disability issues and services in the wake of the Covid global crisis. A brief overview of policy and legislation in Ireland is necessary to understand what rights and obligations the State has to people with disabilities. This will be followed by a brief exploration of living conditions and service provision for people with disabilities pre Covid-19, which will lead to a discussion about the disability landscape during Covid-19. Considering the contemporary situation, a review of emerging studies nationally and internationally will highlight the impact of lockdown restrictions on people living with a disability. In identifying some of these issues, the author will conclude with literature pertaining to inclusion and participation in soliciting the views of people with disabilities as a fundamental human right.

2.2 Disability in Ireland:

2.2.1 The Historical Context:

The concept of disability in Ireland has evolved since the foundation of the state. This evolution is noteworthy in understanding the long and hard fought shift in social attitudes towards this issue. This change reflected the move from a charitable, medical based model of care to a more human rights-based model of inclusion and empowerment (Irish Human Rights and Equality Commission, 2020; Dukelow and Considine, 2017). The importance of moving away from more paternalistic concepts of disability and embracing a rights based, individualistic and person centred response was addressed in the United Nations Convention on the Rights of Persons with Disabilities, 2006. This document asserts that disability comes from "the interaction between persons with impairments and attitudinal and environmental barriers" (United Nations Convention on the Rights of Persons with Disabilities, 2006,

Preamble, (e)). García Iriarte (2016) describes disability as a "complex, multidimensional and contested concept"(p11), thus a person centred/ rights approach helps to more accurately address individual needs. Viewing disability through this 'rights-based' lens is particularly pertinent in the current context of lockdown restrictions. Indeed the 'lens' we use will direct us to where the responsibility lies in terms of service provision and the surety of the delivery of human rights to people with disabilities. For much of the 20th century provision of welfare was largely dependent on a 'mixed economy of welfare' with a "strong emphasis on familial (predominately female) and voluntary (predominately religious) sources" (Murphy and Dukelow, 2014, p13). Many community/voluntary based organisations with religious foundations such as 'The Brothers of Charity' and 'St Vincent de Paul' demonstrate a more secularised Ireland that relies on "Church controlled agencies, even if they are primarily state funded" (Good, 2003, p143).

State funding of community and voluntary based programmes is essential in the delivery of social services. In 2019 Health Service Executives (HSE) allocated a total of 1.904 billion for disability services (Dàil Debate, 8th May, 2019). A report by the Irish Giving Index, 'a non-profit sector tool which tracks and analyses the Irish fundraising landscape in Ireland' estimated that "in 2017, fundraised income for the Irish not-for-profit sector totalled €1.1 billion". The shortfall that is addressed by fundraising initiatives shows that Government departments related to disability services and education have a huge reliance on this sector.

2.2.2 Legislation and Policy:

Ireland's social policy from the foundation of the state in 1922 had been largely influenced by the charitable, medical model delivered by the state or as mentioned above state sponsored religious orders. As such and perhaps not too dissimilar to international policy, a dedicated and focused view of disability policy took much of the 20th century to evolve to include people with disabilities in society. In line with international civil rights advances, evidenced most overtly in America in the 1960s and 1970s, bolstered also by our desire to join what was known initially as the European Economic Community. Domestic policy started to become influenced by external conventions and events " Policy-makers paid special attention to international trends…policy-making had become increasingly interlinked" (Keogh, 2018, p262). The move to a more 'social' model of disability acknowledged that state and society had a responsibility to remove barriers to participation as disability was not solely a consideration of one's 'impairment'. In 1996 the report 'A Strategy for Equality' provided a comprehensive report on the 'status' of people with disabilities in Ireland and would be influential in the Disability Act of 2005, which

included a directive with regard to the assessment of needs of people with a disability. Equality legislation also recognised the shift from a more charitable, medical model to recognising the societal barriers that prevented inclusion namely the 'Employment Equality Acts 1998-2015' and the 'Equal Status Acts 2000-2015. These served to directly address the rights and entitlements of a number of minority and marginalised groups including people with disabilities.

The concept of equality would influence the social model of disability and came to see the provision of support for people with disabilities as an inherent right. Nilsson (2012) purports the need to include people with disabilities in the "existing human rights discourse and tailoring existing rights to fit their needs" (p12). A person centred approach became necessary in acknowledging and understanding the uniqueness of individuals with disabilities thus the necessity to listen to their voices directly which lends itself to a more authentic inclusion.

Ratification by Ireland in 2018 on the United Nations Convention on the Rights of People with Disabilities (UNCRPD), strengthened our commitment to people with disabilities as Article 1 clearly states the need to *"promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms"*

The Education of Persons with Special Educational Needs Act, 2004 compels the support of the principal or organiser of the educational needs "…to assist the child to continue his or her education or training on becoming an adult" (Art 15.1). Furthermore, section 15.2 (b) states the requirement to ascertain the level of education of the individual, or their parents, wishes to obtain. A report published by the National Disability Authority to ascertain the 'the preparedness' of young adults with disabilities after leaving school, highlighted participants feelings that "organisations, such as, employment facilitators provided the majority of the support in relation to transition" (NDA, 2017, P42).

2.2.3 The Disability Landscape in Ireland pre Covid-19:

The challenges for people with disabilities before the Covid-19 outbreak were inordinately greater than people without disabilities in society. The Central Statistics Office (CSO) published a report entitled 'Irish Health Survey 2019- Persons with Disabilities', which referred to people with a disability who were 15 years and older, reported that "43% of persons with disabilities report some form of depression, well above the State average of 14%". (CSO, 2019). A number of pre-budget submissions in 2019 by Irish disability organisations offers a perspective before the Covid-19 outbreak and resulting lockdown. The Disability Federation of Ireland considered the realities for people with disabilities stating that 31% of working age people with a disability were at work compared to 71% of people without a disability.

The same pre-budget report also stated that out of all people with disabilities in Ireland only 0.3% receive a personal assistant service (DFI, 2019). Inclusion Ireland (2020) in their pre-budget submission called for more funding across all aspects of life for people with disabilities. This report called for more investment in educational supports, 100 million in primary care services, the introduction of a 'cost of disability payment' and funding for projects to support young people into jobs. The Irish Times highlighted a funding crisis that threatened the "future of services for up to 65,000 men, women and children" (Keogh, 2019, np).

As the Covid-19 public health response including lockdown measures and their implications, are a relatively new area of consideration for adults with disabilities, the author feels a history of lack of funding in the Irish context for adults with disabilities is relevant. The relevance is that it arguably has had a similar effect, for example, decreased support services, educational and social opportunities. Consideration of the aftermath of the 2008 global banking crisis and ensuing recession demonstrates a political will that appeared to prioritise the business and finance sector "debt that was foisted on Irish society by bankers and the European Central Bank" (Allen and O'Boyle, 2013, p157). The bailout of the banks meant budgetary cuts to facilitate paying back the loan, "Over the course of the Troika bailout, stricter parameters and supervision have been placed on health expenditure" (Nolan *et al.*,2015, np). An Irish Times article from the 9th of October 2020 entitled "Limerick's disability centre's service 'unacceptable' due to funding shortfall" (The Irish Times, 2020, np), highlights the effects of lack of funding for Limerick's day services and its consequences for one family. Watson and Nolan, (2011) in their report 'Social Portrait of People with Disabilities' assert "Apart from reduced opportunities to earn income…people with a disability are also affected by costs associated with the disability itself" (p4). The Disability Federation of Ireland (2020) in the annual report for 2019 highlighted a twenty per cent cut in their funding from the HSE. The chairperson of the DFI implored the government to "make sure that people with disabilities do not again get lost in this nation's recovery programme" (p4).

2.3 The Disability Landscape During Covid-19:

In December 2019 the first reports of a novel Coronavirus (Covid-19) began to emerge from the Wuhan province of China. The rapid and exponential spread of Covid-19 globally saw a comprehensive response by the Irish Government in the form of a 'lockdown' in March 2020. An unprecedented response to an unprecedented global crisis. The initial Level 5 restrictions meant educational and other essential and non-essential services were closed. People were encouraged to stay at home and not to travel beyond a 5km radius of their homes only to acquire essential items. Where possible all services would go 'online'.

Since March 2020 primary, secondary, post leaving cert and third level education has been predominantly delivered online with brief and restrictive returns to on site facilities. By January of 2021, a third Level 5 lockdown had been imposed. An Irish Human Rights and Equality Commission (2020) report in relation to people with disabilities, specifies 'areas of concern'. These areas of concern echo international sentiments in regard to disruption of support services and psychological stress, which will be discussed in the next section (2.3.1), and further adds 'education and employment for persons with disabilities' to the list of concerns.

2.3.1 Mental Health and Isolation

Internationally, concerns began to emerge early in 2020 indicating people with disabilities would be disproportionately affected by lockdown and lack of access to support services, professional and personal (WHO, 2020, UN, 2020). The World Health Organisation (2020) considers the vulnerability of adults with a disability who may be 'disproportionately affected' "… because of serious disruptions to the services they rely on" (p2). Sabatello *et al.* (2020) also consider the workers "who provide direct support in their daily lives has been restricted" (p1524). Tromans *et al*. (2020) consider people with intellectual disabilities to be vulnerable to negatively impacted mental health due to "difficulties accessing services, restrictions brought about by lockdown regulations and fear and anxiety brought about by the pandemic and related media coverage" (p2).

Pettinicchio *et al* (2021) consider the psychological stress associated with Covid-19 lockdown responses for people with disabilities. The authors assert this cohort have "increased sense of loneliness and isolation as a result of the pandemic… report feeling more stressed, anxious, and have a greater sense of despair" (p10). A number of studies relating to 'social isolation' in pre Covid times have linked this isolation to a number of negative physical health outcomes. Smith *et al* (2020) refer to the 'negative ramifications' of 'low social connectivity' which they state have been "equated to the health risks of high blood pressure, physical inactivity, obesity, or smoking 15 cigarettes a day" (p2). Teater *et al.* (2021) consider a number of studies globally evidencing for the general population "significantly higher levels of depression and loneliness during social isolation" (p44). The authors also highlight a study that found "those aged 18 to 29 were more than twice as likely to indicate "high distress" (33%)… during the pandemic" (p46). Constantino *et al* (2020) also attest to the effect of Covid-19 restrictions as extending "far beyond the clinical consequences of infection" (p1093). Integration for people with disabilities is a

relatively new concept as we as a society moved from the segregated practices of the past. Shakespeare (2014) speaks to the 'significantly greater' loneliness that this cohort can experience as they may lack the "energy, skills or resources to socialise" (p191). As lockdown measures continue internationally and nationally, more studies are emerging about the effect this is having on society in general. In Ireland a recent publication from the Central Statistics Office noted the 18-34 age group had the highest reporting of being negatively affected by Covid-19 "Almost three in four (74.4%)" (CSO, 2021).

2.3.2 The Increased Reliance of Online Resources During Lockdown

The potential for online learning has been cited in a number of studies largely relating to students without disabilities, (Tull *et al*. 2017, Greenhow *et al*. 2020). The challenges for students with disabilities are greater with a greater reliance on physical and technical in-person support. UN Rapporteur on the Rights of People with Disabilities in a report states "Virtual learning environments did not (and do not) suit all learners and also serve to expose the digital divide in every society" (Quin, 2021, p10). The type of the course work for people with disabilities also has implications to the suitability of online learning. Practical work experience in training and development courses, for example, has been affected. The longer term effects of this cessation of work experience opportunities highlighted by the National Disability Authority's advisory document noting that "employment is a valuable route to social inclusion, as well as physical and mental well-being" (NDA, 2020, p6).

A Dàil debate (2020) noted the rapid move from on site to online learning at the initial stages of the Covid response. While positive acknowledgement was given to teaching and training staff on this it was acknowledged that online delivery of classes were not preferable, "We found that there is absolutely no replacement for face-to-face learning and people definitely want that" (Oireachtas, 2020, np). In agreement with this sentiment was the CEO of the City of Dublin Education and Training Board stating, "face-to-face contact has not been replaced". Cinquin *et al*. (2019)'s discussion on the efficacy of e-learning state that motivation and engagement with "the learner is a fundamental goal, especially for people with disabilities who tend to have a greater drop-out rate in online distance learning situations" (p31). Greenhow *et al*. (2020), in their comparative study of mainstream students in the U.S and U.K, discuss the 'change in role' for students with increased "responsibility for self-management of learning and increased engagement in activities such as self-assessment" (p13).

The decision to 'lockdown' all but essential services meant the transition to an online provision of many services including education. As Covid-19 and its related public health response is a relatively unparalled

global event, finding similar events and thus relevant data is challenging. In recent years literature pertaining to online learning, by means of such a rapid transition, is comparable to crisis responses to for example natural disasters. Tull *et al*. (2017) called for more a robust and resilient IT infrastructure that is prepared for future unexpected crises which included training and development for teaching staff and students. Their study, based on the effect of the 2011 earthquake on a third level institutions in Christchurch, discussed the importance of "online course sites that can be enhanced should the mode of learning become more blended or off-campus" (p72).

2.4 The Voices of People with Disabilities: Right here, Right now

The Assisted Decision-Making Act, 2015 aims to support "decision-making and maximizing a person's capacity to make decisions" (www.hse.ie). Although passed into law it has yet to be fully enacted as a Decision Support Service is yet to be fully established and operational. The failure of the Disability (Miscellaneous Provisions) Bill of 2016 in progressing is further impeding the Decision-Making Act, 2015 from being fully realised. The Irish State's ratification of the United Nations Convention on the Rights of Persons with Disabilities signalled our commitment. This commitment obliges the Government to ensure these voices are heard. To this researcher's knowledge, the number of reports/publications that directly reference the voices of people with disabilities and their thoughts and feelings on lockdown in Ireland and internationally are relatively sparse at the time of writing.

The 'Build Back Better' positioning paper (Mohamand *et al*. 2020) written in co-operation with Irish Aid and Institute of Development Studies (IDS), speaks to the importance of inclusion and meaningful collaboration as we negotiate the pandemic. This paper calls for policies that include marginalised and vulnerable voices. In obtaining this inclusivity, consideration must be given to 'where the decisions are made, who gets to participate and whose knowledge is prioritized' (Mohamand *et al*., 2020, p5). Gavin *et al*. (2020) echo the necessity of service user inclusion, "During service reform it is also crucial to involve those with lived experience" (p157).

Shakespeare (2021) reinforces the importance of ensuring the pandemic does not further alienate people with disabilities from "the COVID-19 response…throughout all post- recovery stages by assessing their needs and ensuring that they are consulted" (Shakespeare, 2021, p2). The absence of direct engagement with people most affected by lockdown and their thoughts and feelings is notable. Rajkumar (2020)'s review of literature pertaining to mental health and Covid-19, he notes the majority of literature is

comprised of "letters to the editor and editorials or commentary related to mental health and Covid-19" (p2).

The UN Rapporteur on the Rights of People with Disabilities states in his report that "old service models were too fragile and lacked critical continuity during times of crisis" (Quin, 2021, p15). The link between disability and poverty is documented in a report from the European Disability Forum. The report rates Ireland unfavourably in terms of the vulnerability of Irish people with disabilities to poverty at 38.1 %, compared to the European Union average (European Disability Forum, 2020, p18). In a broader context Banks *et al*. (2018) consider the need for interdepartmental thinking and to "not just rely on social security or social welfare" but that "responsibility also lies in education and employment policy" (xi). A press release by The Disability Federation of Ireland, in response to the Government's 2021 budget announcement, stated that although it allocated an extra 100 million to funding disability services it was not sufficient in covering costs. The reality is the "near collapse of disability services hit by…extra Covid-19 costs and a collapse in fundraising for the 80% of services provided by the voluntary sector" (Disability Federation of Ireland, 2021).

2.5 Conclusion

The global pandemic and resulting lockdown restrictions have universally had negative psychological impacts across all sections and ages of society. The literature provided has attempted to highlight the challenges to people with disabilities pre Covid-19 but in particular during the public health restrictions. Several studies cited in this literature review discuss how people with disabilities are disproportionately affected in comparison to the general population. In providing a brief historical context in regard to the experience of people with disabilities one can see the importance of hearing the voices of this cohort, which have been overlooked in the past. Capturing their experiences to inform future service planning and development is vital. State and societal facilitation of this is obligatory within a human rights framework. The overarching aim of this research therefore is to document the views, thoughts and feelings of the participants to understand in real time the effect the pandemic is having on this group of young adults.

Chapter 3: Methodology

3.1 Introduction

The following chapter will discuss the processes the researcher engaged with in regard to retrieving and analysing the data. The author will discuss theoretical underpinnings that informed the ontological and epistemological aspects of the research followed by the methods employed in gathering and analysing the data. A brief discussion with regards to this researcher's limitations in carrying out the research as well as ethical considerations will also be discussed.

3.2 Ontology

Ontology is described as "the nature of social phenomena…and beliefs …about the nature of social reality" (Denscombe, 2010, p118). Constructionism purports that organisational and cultural meaning pre-exist for researcher and subjects. Through social interaction "phenomena…are produced…they are in a constant state of revision" (Bryman, 2012, p33). A constructionist view is appropriate for this research, the author believes, as it acknowledges the subjectivity of the person's experience and values their unique perspective.

3.3 Epistemology

Epistemology is concerned with "the nature and forms of knowledge" (Thody, 2006, p98).

Bryman (2012) asserts that 'Interpretivism' offers an epistemological framework that affords the researcher a procedure that "reflects the distinctiveness of humans against the natural order" (p28). For the purpose of this research interpretivism acknowledges the importance of the participants' personal experience and the meanings they attach to it. This is important in understanding the participants' points of view.

3.4 Methods/Research Sample

Participants were asked to write letters about their experience of lockdown. Guiding questions, see appendix I, were offered to encourage the participants to express their feelings. Due to time constraints and academic deadlines, it was decided in consultation with the community partner, the researcher and

the academic supervisor, that a cut-off date for submission of letters was necessary. Twelve participants in all make up the study group. The time period for collection was January 2021.

Qualitative research seeks to provide a more in depth view of research. In comparison to the quantitative approach that considers numerical data, qualitative is concerned with "rich, or 'thick' descriptions of social life…and 'experience the world from their point of view" (Geertz, 1973 cited by Gomm, 2004 p13). Bryman (2012) asserts this form of analysis considers how people make sense of what happened as opposed to "what actually happened" (p582). A qualitative approach was deemed appropriate by the researcher as the thoughts and feelings of participants were key to understanding their experiences of the pandemic.

3.4.1 Primary Research

The primary data was in the form of letters written by participants. The use of letter writing as a medium of expression was used in response to the restrictions on participants meeting in person but also as a less invasive way of gathering information in 'real time'. Stamper (2020) asserts that "research subjects may feel less exposed, as people, if they write, rather than speak" (Letherby and Zdrodowski, 1995 cited by Stamper, 2020, p179). This correspondence method offers a live and in real time documentation of participants' thoughts and feelings. Considering lockdown by means of a revisionist research may lose authenticity through forgetting or perhaps a desire to move on from a challenging experience.

3.4.2 Secondary Research

The literature review, as outlined in chapter two utilises books and journal articles, historic and contemporary to give a wider context to the concept of disability. It also includes a number of community/voluntary/advocacy group publications and press releases to provide a more accurate indication of the voices of people with disabilities in the absence or lack of availability of studies directly documenting these voices.

3.4.3 Sampling Method and Recruitment

All participants in this research are students on the 'PACES' programme run by the National Learning Network. Purposive sampling was used to include male and female participants and to offer a representation of the group. The students were made aware of the involvement of University College, Cork and that their letters would be used as part of a mixed media style exhibition. Students were free to participate and signed consent forms, see appendix II, by all participants were witnessed by this

researcher. After discussion with the agency liaison, it was decided throughout this report participants would be given alphabetical pseudonyms.

3.4.4 Data Collection

Letters were sent from the participants to the agency liaison worker which were received by the researcher throughout January 2021. The letters of those who did not want to participate in the research were not sent to this researcher by email. Time constraints meant a cut-off date in early February was agreed by the agency liaison, academic supervisor and the author. The participant group, therefore was n=12.

3.4.5 Data Analysis

Narrative analysis as a means of qualitative research seeks to "make sense of storied data" and can offer a way of understanding "what is said in talk and how things are said" according to (Smith, 2008 cited by Braun and Clarke, 2013, p197). As these letters do not reflect a two sided conversation, the author feels narrative analysis speaks to the concept of storytelling as it "rarely deals with the interactional business being accomplished" (Smith, 2008 in Braun and Clarke, 2013, p198). Polkinghorne's (1995) description of narrative speaks to its utility for this research " the primary schema through which human experience is made meaningful." (p125).

3.4.6 Thematic analysis

Thematic analysis provides a way in which to identify, analyse and report "patterns within data" (Braun and Clarke, 2006, p79). The views of the participants were of utmost importance therefore an inductive or data driven approach was utilised. Furthermore the researcher aimed to consider more semantic themes to represent closely the views of the participants.

3.5 Limitations

The Government's Covid-19 public health response meant Level 5 restrictions were in place for a significant time during this research. This researcher had hoped to carry out a maximum of three in-person interviews but it was decided at a meeting with the community partner and the academic supervisor that this would not be possible due to time constraints.

Researcher bias is also a consideration as this researcher could draw parallels with the research participants being students and having to work remotely. As mentioned earlier in this chapter the author

has included direct quotes from participants to ensure the sentiments of the participants are not misinterpreted by the researcher.

The author also acknowledges that the participants in this research represent a small cohort of a much larger and diverse population. Word count and time constraints also account for limitations on this study due to academic commitments and requirements from the University.

3.6 Ethical Considerations

Ethical considerations have been addressed by acknowledging the fact the participants are considered vulnerable. However, all participants in this study are over the age of eighteen years it is acknowledged they are young adults with disabilities. As a social work student, the author considers a rights-based framework that is person-centred as being a fundamental value when working with people. Rights-based theory promotes the empowerment of individuals. The National Learning Network liaison worker discussed the idea of writing letters with the service users as a 'less invasive' way for them to express their feelings during the pandemic. See appendix II for agency liaison supporting letter. In this regard, the researchers hoped participants would have "a sense of control to the point at which the process can even become cathartic (Meth, 2003 cited by Stamper, 2013, p180).

The author is aware the term 'people with disabilities' is used throughout this research but acknowledges that for some people terms like 'differently abled' or 'neuro-diverse' could also be used. The author has used the term 'people with disabilities' after consulting the community partner and academic supervisor. The author understands the term disability is a generic one and should always allow for personal interpretation from the individual in how they would like to be identified.

The students were informed that the letters they wrote would, with their permission, be used as part of an art based exhibition, using different mediums of expression to highlight their experiences. Furthermore the National Learning Network liaison outlined supports available to students namely key workers and a psychologist on hand to assist participants. These commitments and actions by the National Learning Network liaison have been documented in a supporting letter (see appendix II). All data will be deleted in line with college regulations with regard to data storage.

Ethical consideration was also given by the author's supervisor from the Social Work Department in the School of Applied Social Studies in University College, Cork to further interrogate the research and ensure the highest quality of care was given to participants and their words.

3.7 Time Scale

Stages of Research	Starting Date	Finishing Date
Conception and planning	September 2020	December 2020
Carrying out Research	January 2021	February 2021
Gathering and analysing data	February 2021	March 2021
Writing of report	March 2021	April 2021
Submission of report		April 2021

3.8 Conclusion

This chapter aimed to recount and rationalise the way in which this research was carried out. The motivation and manner in which this research was carried out from inception to completion at all times used a rights based approach. Through this framework, the researcher was mindful of respecting the dignity of research participants by providing a non-judgemental and confidential approach to the information contained within the data.

Chapter 4: Data Analysis and Findings

4.1 Introduction

The following chapter identifies the findings of the research. These findings are based on data contained within letters written by the participants, (n=12). The overall aim of the research is to document 'the lived experiences during the pandemic of young adults with special needs in Cork'. The participants in this research are adults between the ages of 18-25 years of age who are students of the 'PACES' programme facilitated by the National Learning Network. The National Learning Network offers a number of training courses and support services for 'people who need specialist support'. People with a disability are included in the National Learning Network's target demographic.

The 'PACES' programme aims to 'enhance independent living skills' and 'employability skills' and the attainment of QQI level 3 qualification. The rapid and exponential spread of Coronavirus, from its initial identification in China in late 2019, meant a swift and comprehensive change to people's lifestyles and choices globally. In Ireland since March 2020, Level 5 restrictions have been implemented, as of February 2021, for a third time.

As referenced in the literature review, society has been majorly impacted due to these restrictions. The use of letter writing was deemed a less invasive way of understanding and highlighting the lived experience of the participants in this study. Capturing the contemporaneous experience of participants can offer a more visceral account of their experience of lockdown, as opposed to a retrospective piece that may be lost in the accounts of different social groups nationally and internationally.

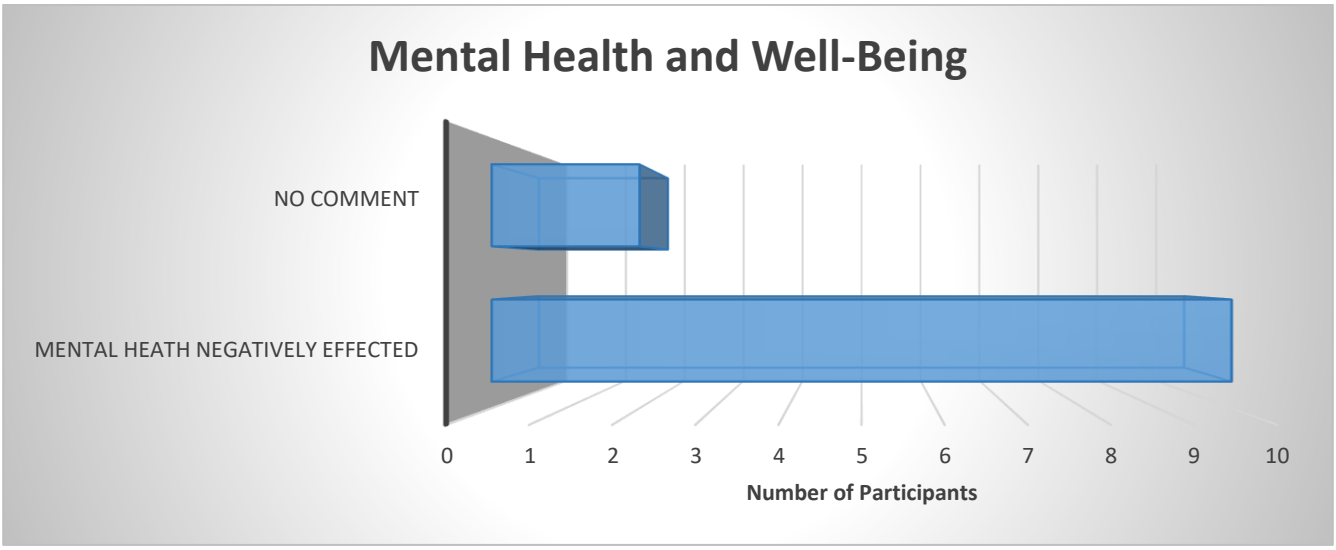
Guiding questions, see appendix I , were offered by NLN key workers to encourage students to express their thoughts and feelings of their lockdown experience. A qualitative approach helped this researcher to consider the sentiments expressed by participants. The researcher used thematic analysis as a means of identifying common themes. Braun and Clarke (2006) consider 'prevalence' as one aspect of choosing a theme. Furthermore as this research uses primary data, a more inductive position informs this researcher's motivation to capture the opinions and feelings of the research subjects. Using thematic analysis the following themes were identified : (1) 'Mental Health and Well-Being', (2) 'Remote Learning and Technology' and (3) 'The Perceived Positives of Lockdown: Finding Resilience'.

4.2 Mental Health and Well-Being

In May of 2020, O'Connor *et al*. described what they anticipated as a "tsunami of mental health need will arise sometime after the initial pandemic peak, will persist for months to years" (p1).

Gavin *et al.* (2020) consider the 'stark reality' of such changes for society in general but keenly acknowledge that vulnerable groups will be 'disproportionately affected' from the 'mental health fallout'. Emerson *et al*. (2021) found that people with disabilities were "more likely than their non-disabled peers to report loneliness,… social isolation and to report… low social connectedness" (p4). Theis *et al*. (2020) in their research with 'children and young adults with physical and/or intellectual disabilities' call for further scrutiny and research into this vulnerable cohort. Their study concluded an overall negative impact on the 'physical activity and mental health' of their research subjects. Theis et al. impart the importance of this scrutiny to "ensure the imposed restrictions do not have lasting consequences" (p7).

> *"Just a passenger on the COVID-19 train, and the tracks, well, the tracks feel like they never are coming to an end"*(Participant I)



4.2.1 Low mood and anxiety

Considering this primary data, eighty-three percent (83%) of participants referred to their mental health as being affected by the change to their routine and lack of personal choices due to restrictions.

Participant A comments on this change stating

> "*for some it's been an alright transition but it wasn't for me. I have always struggled with my mental health but this pandemic highlighted how badly I needed help*".

Participant D expresses concern for his mental health and feels

"*the current situation amplifies thoughts and feelings*".

Participant K describes his concerns namely for his sister as "*she has many health issues*", his family finances due to Covid restrictions on businesses and his contraction of Covid-19 which meant being isolated from his family "*for two weeks which was mentally draining".*

Participant G writes

"*If I could change anything from this experience I would try and have a positive outcome and start thinking more about my health and well-being."*

Overwhelmingly, all participants referred to dissatisfaction with restrictions on their daily lives due to Covid-19.

Participant B states

"*Since the Covid pandemic came into Ireland my mood swings have being affecting me. If these lockdowns went away , I'll be away more happier in myself*"

and considers the lockdowns were

"…*stressful*…" causing her to become "*worked up with not going anywhere*".

Participant I refers to the longevity of the imposed restrictions stating

"*I'm trying to think of the good things about last year, however far and few between…it's difficult".*

4.2.2 Change and Uncertainty

Ten out of twelve participants (83.3%) refer to the change and uncertainty in their lives due to Covid-19 and the resulting public health measures.

Participant A writes

"life has changed so much, the normality we had before Covid-19 is long gone…schools and colleges are constantly being closed and reopened".

Participant B considers how this change has affected their life

> " *also with the lockdown my sleep schedule was all over the place and had no energy to do anything"*

Participant C reflects on the dramatic change in their life

> "*This pandemic has been crazy…Lockdown is going to last way longer than we thought I'd say"*

Participant D further elaborates on the implications of the restrictions for him

> "*I also found it hard to plan for the future as there is so much uncertainty. Young adults like me are in the position where it feels like some of the best years of their lives are moving in slow motion or aren't moving at all…which is very stressful. I just hope I can make up for lost time in the near future".*

Participant F succinctly describes the lockdown from their own perspective

> "*I could not go outside freely, I had to cease my usual activities*".

Participant I reflects on their life before and after Covid-19 lockdown restrictions

> "*I'm always one to try to experience something new or different, but after almost a year of Covid, I can say with certainty I'd rather not be dealing with it at all".*

Participant K also considers the change in their life

> "*Covid-19 has affected my life…not being able to do the small things in life… to having to adjust to completing coursework from home".*

4.2.3 The Importance of Having a Routine

For many people having a routine provides predictability and a sense of comfort as a result. The Health Services Executive offer advice for young people in minding their mental health during Covid-19. "Routines give children and younger people an increased sense of safety" (www2.hse.ie). Colvin and Lazar (1995) discuss the advantages of class routines and cite positive outcomes such as the encouragement of 'self-management skills with opportunities to practice these skills' (p75). Reference

was made by a number of participants, twenty-five per cent (25%), in the primary data to missing their usual daily routine or creating a new routine after lockdown restrictions were enforced.

Participant A clearly states

"*my energy levels are often quite low so for me to go from my routine…it hasn't helped"*

Participant B has a similar issue

"*had no energy to do anything , so made myself get up at a certain time to go for a walk"*.

4.2.4 Family and Friend Support

Ten out of the Twelve participants (83.3%) who contributed to the primary data used in this research, commented on the importance of family and friends. Either through direct attribution of their support or by noting the effect of their absence. International research for example Emerson *et al*. (2020), Teater *et al*. (2021) and nationally Inclusion Ireland (2020) consider the vulnerability of people with disabilities to loneliness and anxiety as a direct result of a diminished connection to family and friend supports.

Participant A describes the experience of not being able to see their close friends or brother as 'horrible'. They also state because they were

"not with family or friends it could be quite lonely sometimes"

Participant B reflected on the enjoyment, during an ease in restrictions during Christmas of 2020, of being able to

"*go to cafes with my friends and have a drink and food and to go out at weekends with my friends*"

and how they looked forward to being able to *"hug our friends again too*".

Participant D felt that

"*Not being able to see friends as often was very weird*"

but cited the importance of their family

"Being able to relate to them during this tough time helped".

Participant F considers that

"*My parents and my younger brother helped me during this difficult time for all of us"*

Participant G explicitly states

"*I miss socialising with some of my friends because they are the only people who keep me going".*

Participant J prefers to

"*go into a classroom and meet your classmates and your keyworker as I'm a quiet person in general"*

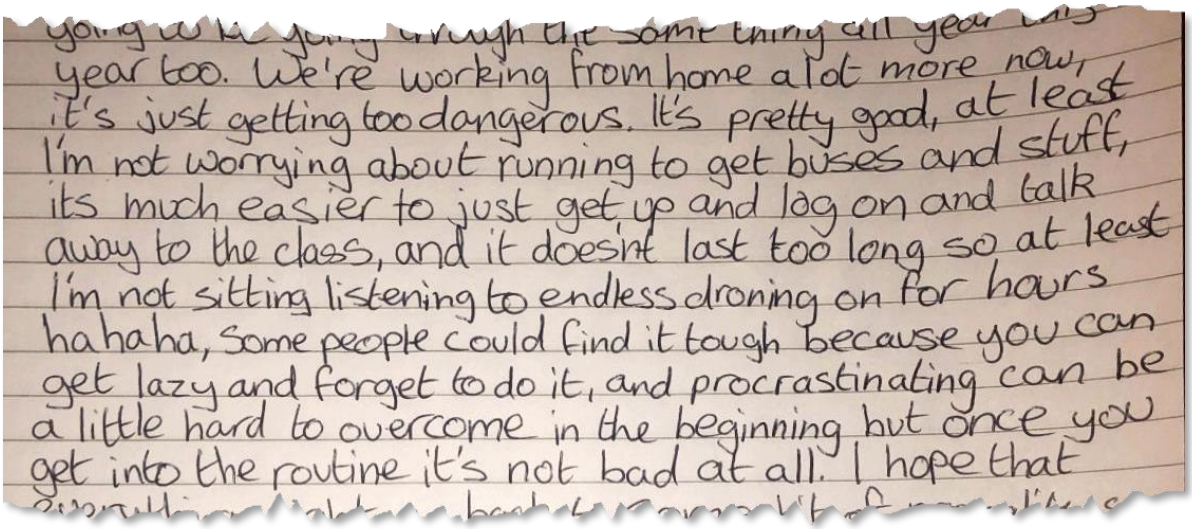
Participants L writes

"*My family were mainly there for me*".

Remote learning and technology will be discussed in the next section as another theme identified throughout the participants' letters. Their perceived quality of their educational experience during Covid but could have been cited in this section as participants comment on the importance of interacting with their friends in class.

4.3 Remote Learning and Technology

As discussed previously the sudden and life altering responses to the Covid-19 pandemic has had a huge impact on their day to day lives and educational and social opportunities of the research group. The lockdown measures have meant remote learning has been employed since March 2020. For the National Learning Network students of the 'PACES' programme, since March 2020 , the majority of their class time has been through remote learning. Social distancing requirements coupled with physical classroom sizes, has meant for some classes have had to rotate their students' on-site attendance during lockdown. Eight out of the twelve (75%) participants directly expressed a preference for on-site learning. This is echoed internationally, (Day *et al*., 2020; Bryson and Andres, 2020), in the limited number of Covid related studies beginning to emerge. 'Many' students "found it difficult to be motivated by remote classes. The lack of community, the sense of isolation, missing their friends" (Day *et al*., 2020, p6)



4.3.1 Online Learning

While it is acknowledged that online learning has provided an adequate response to the swift and unprecedented lockdown measure during the Covid-19 pandemic, the majority of participants seventy-five per cent (75%) preferred on site learning. Many of the participants in this research acknowledge that online learning gives them an opportunity to engage with their classes as lockdown restrictions continue. The efforts of teaching staff is commended by Participant K-

> "*Although the whole team from the centre have done everything possible to help me…it has been difficult".*

Participant H appreciates that technology does keep her connected to classmates

> "*It is good that we have the MS Teams meetings all the time so I can talk to everyone".*

Four out of twelve (33%) of participants found it hard to focus on course work online.

Participant B comments on working from home ;

> *"too many distractions plus I lose concentration on my work and sometimes forgetting to do the work".*

Participant C adds

> "*procrastinating can be a little hard to overcome in the beginning*".

Other participants remarked

"I had a huge problem with focussing on my job and get into a new routine" (F)

"*I find it much harder to stay focused*" (K).

The prolonged process of submission and feedback as expressed by Participant K provides a challenge

"your assignment, you have to have it all done and email it back to the teacher which is harder for them to correct it and then email it back to the student again to fix it or change something".

Day et al., (2020) drew similar concerns in their study when it was noted that for some subjects "a simple question turned into a lengthy e-mail trail as students struggled to express what they did not understand" (p6).

Participant I and L did not comment on their experience of online learning.

Participant E was the only subject who explicitly expressed the preference for online learning. They state

"*I don't have to go in… I like that we can now sleep in more and go to bed later"*.

This researcher will consider this statement in an upcoming section, 'The perceived positives' (4.4.3)

4.3.2 Benefits of in-class learning

The research participants expressed a number of reasons for preferring the in-class experience. There are a number of sentiments expressed by students in the preceding section relating to what was difficult for them about online learning. This could indicate what they missed about face to face learning. The author in this section will use explicit references to being in class.

Participant B comments on the benefits of being with classmates as she feels

"you can learn away better from listening to other students"

Participant D felt that remote learning lacked

"the face to face element of learning which is…a lot easier to properly communicate".

Participant J also comments on communication issues for them using online learning. They state:

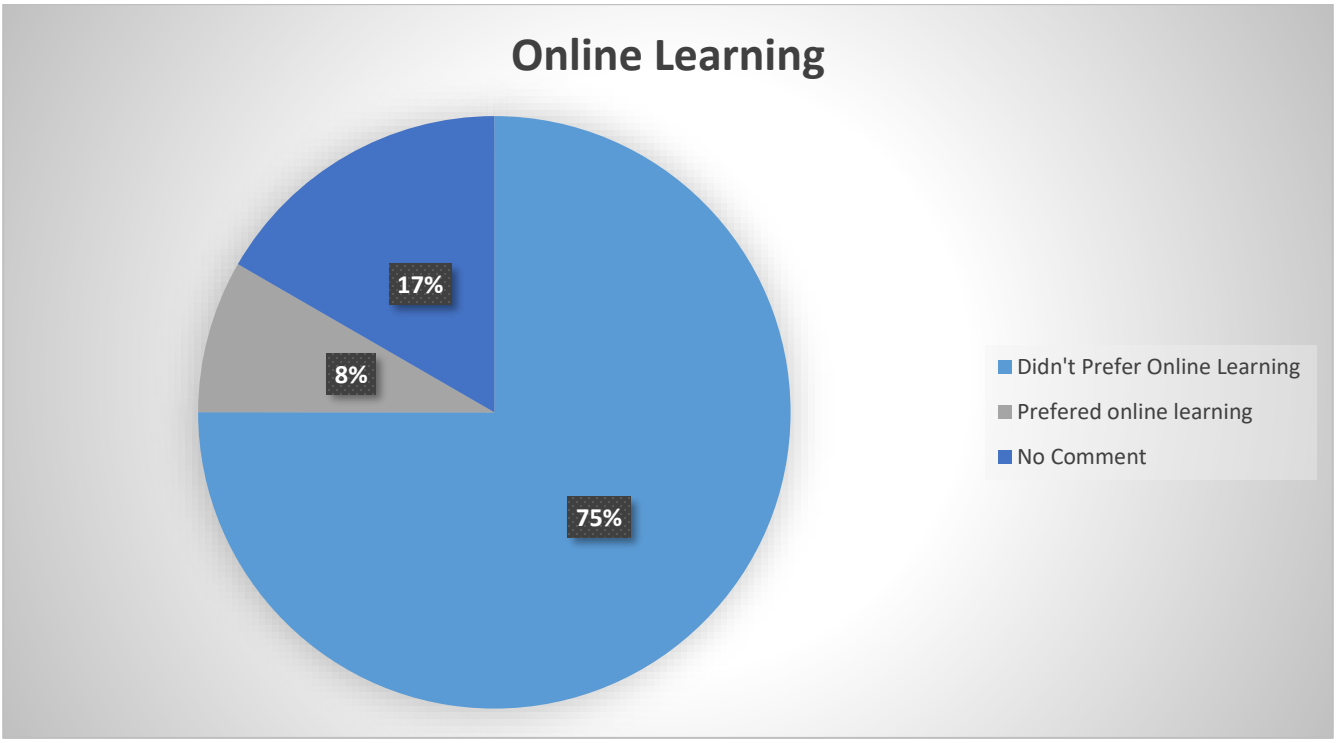
" *I'm not really a fan as I find it stressful as I find it quite difficult to express my feelings and thoughts"*.

Participant K states that he

"finds it much harder to stay focused…when not having the environment of the centre to attend".

Participant F also cites lack of concentration as an issue

"I had a huge problem with focussing".



4.3.3 Lost opportunities of work placement

Four out of twelve participants (33%) directly commented on their inability to complete the work placement portion of the course.

Participant B recalled

"*I found it hard to get into places cause no one was taking any person on for work experience".*

Participant C writes

"*I was in the process of getting a job which was quickly cancelled, I hated it and I was really looking forward to it".*

Participant K expressed disappointment at this as well as concern for the future;

> *"Unfortunately I have not been able to complete any work experience" "I do worry this will have an effect not only on my social skills , but my missed opportunity in getting some experience in an area of my interests".*

Concern for the future is also expressed by participant D

> "*I just hope I can make up for lost time".*

4.4 The Positives of Lockdown: Coping Strategies and Resilience

Covid-19 restrictions have caused anxiety and depression amongst the general population globally (Pettinicchio *et al*., 2021; Tromans et al., 2020; Smith *et al*., 2020; Teater *et al.*, 2021). This has been replicated in the participant group for this research, discussed previously in the section Mental Health and Well-Being. The data described below shows seven out of twelve participants (58.3 %) commented on their gratitude. One of the guiding questions, see appendix I, suggested to the participants was "what helped you most during this time?". Although participants did not answer the guiding questions in a questionnaire format, it perhaps indicates how the concept of gratitude features in the participants' letters. As lockdown restrictions look set to continue, with uncertainty in 2021, coping strategies will continue to be necessary. Eleven out of the twelve participants (91.6%) in this study expressed positive feelings toward some aspect of their lives. The following attempts to document the more prevalent positive themes in the participants' letters.

4.4.1 Gratitude

A number of studies discuss the positive effect of gratitude on ones well-being; Rash *et al.* (2011) concluded that "…contemplating grateful thoughts appears to have resulted in…reducing stress and boosting well-being (p364). Wood *et al* (2010) asserts 'several studies' "have shown that gratitude correlates with well-being and social relationships" (p7).

Seven of the twelve participants, (58.3%), expressed gratitude explicitly. Five of these participants cite being thankful for family and friend supports.

Participants D writes

> "*I am grateful for my family at home and the technology that allows me to speak to friends online".*

Participant F discusses their familial support during lockdown by stating

"*I am really grateful for their presence in my life"*

Participant K remarks

"*As a family we have had to pull together*"

Participant L states their family was

" *there for me*"

Lockdown restrictions for participants meant missing activities but increased gratitude for outings or events that could take place during eases in restrictions.

Participant I states,

"*The few times I've gone out to eat somewhere nice the previous year has been treasured".*

Participant D also considers how the lockdown has inspired their outlook on life

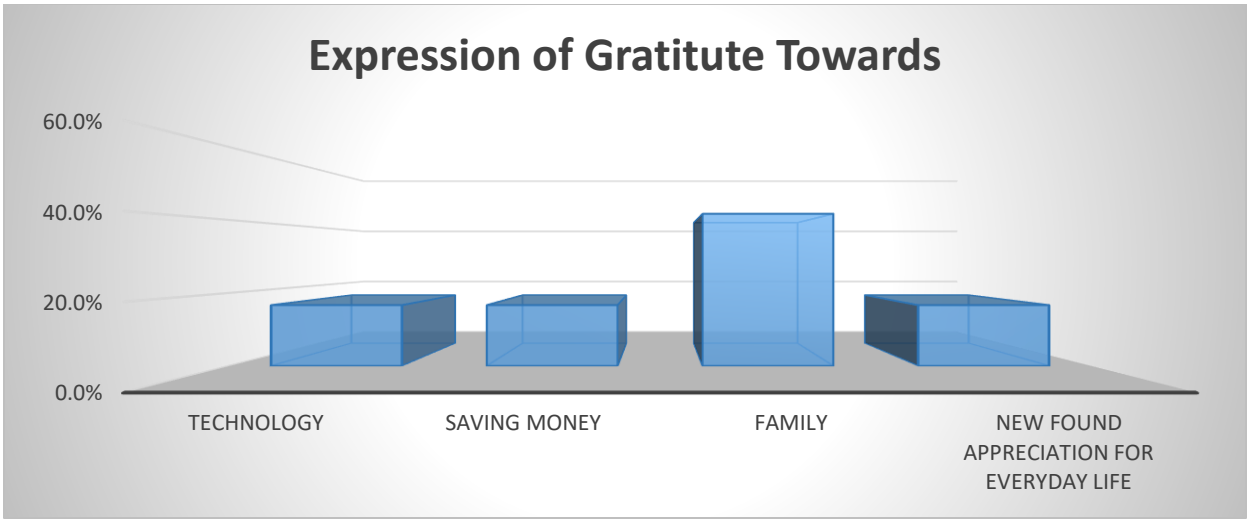
"*I'll definitely take opportunities and not pass them off* ".

Participants A believes spending time at home during lockdown

"brought me closer to my roommates".

Participant B expressed gratitude for the technology that allows her to learn remotely

" *I can talk to everyone".*



4.4.2 Introducing a New Activity or Interest

Park *et al.* (2020) found in their research related to Covid-19 and stress that the "most common coping strategies were distraction, active coping, and seeking emotional social support" (p2300).

A significant percentage of the research subjects, five out of twelve (41.6%), refer to the importance of finding a new focus or distraction to counter the negative effects on their mental health of lockdown.

Participant A discusses their 'healthier lifestyle' which included dietary change.

Participant B extolled the virtues of going

"for a walk to get fresh air into my lungs".

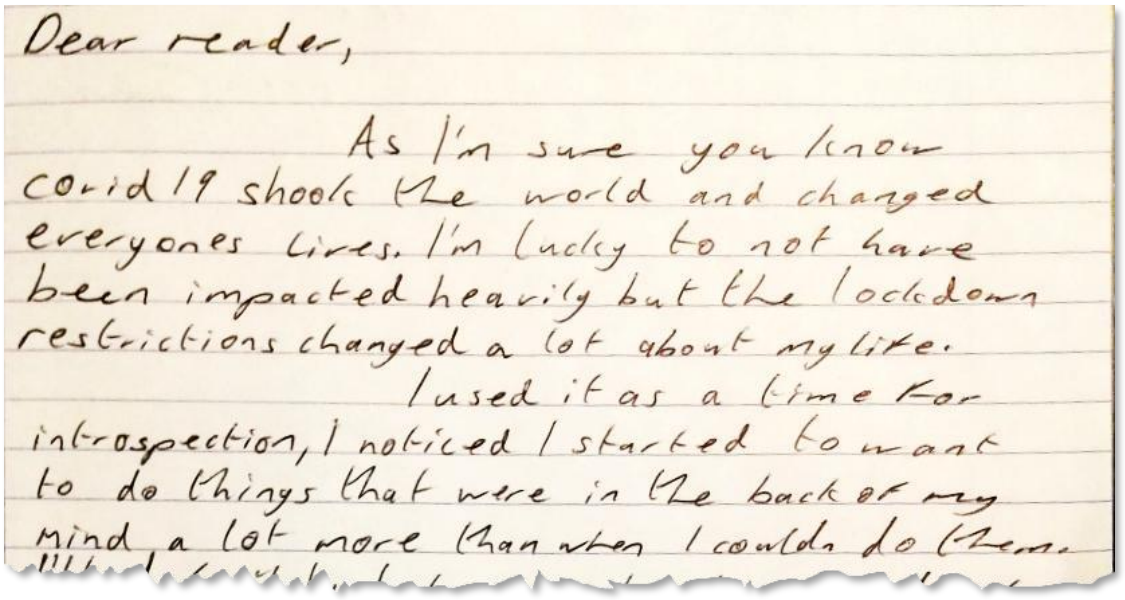
Participant D learned to cook and started to do Yoga.

Participant G also learned to cook and offered the opinion that, could they in hindsight change anything about the lockdown experience, they would

"*start thinking more about my health and well-being*".

Participant K felt keeping busy was helpful to distract from the anxiety that the uncertainty of Covid-19 had brought, for example

"working in your garden, reading, working on new skills or taking up a new hobby".


Dear reader,

As I'm sure you know covid 19 shook the world and changed everyones lives. I'm lucky to not have been impacted heavily but the lockdown restrictions changed a lot about my life.

I used it as a time for introspection, I noticed I started to want to do things that were in the back of my mind a lot more than when I could do them.

4.4.3 The Perceived Positives of Lockdown

For a number of participants learning from home was perceived as a positive, even amongst participants who stated that they preferred on site learning.

The convenience of

"*not running for buses*." (Participant C)

Participant E's relief of not going into class as it

"makes my anxiety a lot easier".

Participant G feels that Lockdown has "*made me build a bit more confidence*" in terms of engaging with online communication while also stating that he has been

"spending most of my time in my bedroom"

Participant L expresses this ambiguous positive of lockdown by stating that she found 2020 'alright' because she

"*got to stay at home a lot, although it got frustrating , I didn't mind it".*

Participant E echoes this duality also as they consider being

"*stuck inside more than I'm capable too mentally*"

but conversely likes remote learning as they don't have to 'go in' [to the centre].

4.5 Conclusion

The chapter aimed to deliver the predominant themes contained within the letters written by research participants. Conveying the participants' words accurately was paramount for the researcher evidenced by the use of direct quotes throughout. The researcher's reflections and recommendations inspired by these letters will be documented in the next chapter.

Chapter 5: Recommendations and Reflections

5.1 Introduction

The following chapter will consider the main findings of the research with recommendations from the researcher inspired by the study.

5.2 Key Findings

5.2.1 Mental health and well-being

According to the primary data in this research, eighty-three percent (83%) of participants commented on the negative effect lockdown restrictions had on their mood. As out outlined in Chapter 4 there were a number of reasons for this according to the participants. Isolation from family and friends was common amongst participants as something they missed. Change and uncertainty also contributed to participants' anxiety, coupled with the loss of routine which was also deemed important in keeping students focused.

5.2.2 The challenges of online learning

Seventy-five per cent (75%) of participants expressed a preference for on-site learning. Reasons for this preference, thirty-three per cent (33%) were focus and concentration were challenged due to the lack of a more interactive and supportive on site experience. A further 33% specifically state their preference for face to face learning as it is easier to communicate. Will this group be impacted unfairly in the future having not been able to maximise the opportunities this course usually offers students? The implications for students in regard to the disruptions that lockdown has had on their lives and education needs to be considered and addressed. Also mentioned by thirty-three per cent (33%) of students was the disappointment of not being able to carry out their work placements. Four out of the twelve (33%) participants explicitly refer to missing seeing their friends in class which is mirrored in the previous section on mental health and well-being.

5.2.3 The positives of lockdown: resilience and coping

Lockdown restrictions have been difficult for participants as demonstrated in the previous sections (5.2.1, 5.2.2). In spite of the negative impact caused by isolation and change and uncertainty, seven out of twelve (58%) of participants expressed gratitude for predominantly family and friends.

Five out of twelve participants (41.6%) refer to the introduction of a new activity or hobby as a way of improving their well-being.

Four out of twelve (33%) referred to the convenience of not having to leave the house to physically attend their classes. The author referred to this as a perceived positive and will elaborate on this in the Recommendations section 5.3.3.

5.3 Key Recommendations

5.3.1 Funding of services and supports as a right not an after thought

As demonstrated in the wake of the 2008 banking crisis and recession, the potential impact of Covid-19 on budgetary expenditure may have a negative effect on the funding of services for people with disabilities. As of yet in Ireland it is unclear what the financial implications are of this lockdown. Furthermore Britain's withdrawal from the European Union and its implications for Ireland's economy must be considered.

5.3.2 The potential of online resources for people with disabilities

As mentioned in the Literature review, online learning may not suit everyone but there may be potential to use it to enhance learning through a blend of on site and online learning. Those with extra learning needs will continue to require one to one interaction that, according to the majority of the participants in this research, is most effective for their needs. The financial uncertainty may place a strain on supports and services, online learning may provide more accessibility to people with disabilities to training and education courses.

5.3.3 The need for community and connection

The cooperation of local businesses in facilitating work placements, and crucially paid employment, is essential and needs continued support through Governmental incentives. Visibility for adults with disabilities lends itself to integration and a more authentic participation in society. For participants of the 'PACES' programme 'enhancing independent living skills' and 'enhancing employability skills' are core aims. The experiential nature of having a work placement is fundamental to enhancing employment skills. Negotiating public transport and adhering to time schedules similar to class time at the National Learning Network on site facility, also provides key learning and planning for students. Staying at home takes opportunities from participants to challenge themselves and learn new skills.

All participants to varying degrees refer to the negative effect on their mental health and well-being due to isolation as was discussed in 5.2.1.

5.3.4 Further in-depth research on the effects of Covid post Lockdown

In carrying out this research I was shocked to read the huge disparity in terms of rates of depression amongst people with disabilities in that they were much higher than people without disabilities, 43% for people with disabilities compared to 14% as the state average (Central Statistics Office, 2019). As this survey was conducted pre Covid it is concerning to speculate how this may have increased. In February 2021 the Central Statistics Office carried out a survey amongst the general population which reported 74.4% of those aged 18-34 reported a negative effect on their mental health due to the pandemic. It is imperative to carry out a study specific to people with disabilities to highlight the disproportionate effect lockdown has had on this cohort.

Along-sider research is a term given to an inclusive form of research that involves the participants or research subjects as co-authors "working alongside each other" (Chalachanová *et al*, 2020, p147). As discussed under the heading of Limitations in Chapter 3 -Methodology, the inability to carry out face to face interviews was extremely disappointing for this researcher. To develop a deeper understanding of the effects of lockdown on participants further conversations needs to be had "investing time in building such relationships… is important for researchers doing research inclusively with people with intellectual disabilities" (Chalachanová *et al*, 2020, p155). Revisiting this cohort at different times pre and post lockdown is essential to properly understand their needs and thus be ready to implement a plan as we start to open society again.

5.4 Reflection

The process of carrying out this research has been challenging and rewarding for the author. As a student myself, I found parallels with the participants in this research for example, the challenges of online learning, the frustrations of lockdown restrictions and the need to find ways of coping. As a person without disabilities, I can attest to how challenging Covid-19 has been, but through this research I have come to understand that the implications for me are very different. The participants in this study offer their experience of lockdown and also offer, according to the author, valuable advice on coping. This cohort have the potential to contribute and participate in all sections of society, in particular the concept of 'along-sider' research as outlined in 5.3.4. Although referred to as participants throughout this study, the letters written by the National Learning Network students informed every aspect of this research and as such the term 'co-authors' would be just as accurate.

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Chapter 7: Appendices

Appendix I

1.What was the best thing about the lockdown?

2.What was the worst thing about the lockdown?

3.What did you miss the most and why?

4.Did you learn any new skills during this time?

5.If you could change anything about your experience of Covid or the lockdown, what would that be?

6.How will you remember 2020?

7.What helped you the most during this time?

8.What space did you spend the most time in and why?

Appendix II

National Learning Network
Investing in People, Changing Perspectives

TO WHOM IT CONCERNS

I _____ consent to taking part and submitting personal data to the CARL research project, Letters in the time of Covid. I understand that the content of my letters will be used for research purposes and may be published.

Signed:

Date:

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Appendix III

National Learning Network

Investing in People, Changing Perspectives

To Whom It May Concern,

My name is Roslin Treacy and I am an instructor with the Employability Skills course in the National Learning Network. I am writing this letter as a support for Loretta Sweeney's research thesis "**Letters in the Time of Covid": the lived experiences during the pandemic of young adults with special needs in Cork**. The National Learning Network is presently conducting a research driven art project entitled "Letters in the time of Covid". The concept behind this project is to underline Covid's impact on our service users and their disability support services during lock down. The project will work with 22 students from the Employability Skills Course. From these students, Loretta will collect data on and interview three students.

The Employability Skills Course works with young people with disabilities and assists them in entering into the world of work. Our students range from the age of 16 -25 years old. However, all participants of the project will be 18 years old and over. NLN has conducted other projects like this whereby our students express their experience in society and the work place. Projects such as "Feel the Difference" and "This is me" served as a positive and non-intrusive platform where students express their thoughts on disability and their personal experiences. Projects such as this encourage our students to self-advocate, develop generic work skills, and expand their experience within our local community.

Loretta's academic input will provide invaluable insights to this project as we capture young adults with disabilities experience to Covid and the "new normal" in real time. I have discussed this project in-depth with all student participants and they understand that their work will contribute to University research. Documentation of their consent to the project is readily available. In addition, all of our students have been deemed as training ready by NLN's admission committee and we provide a solid support team which include a learning support worker, Rehabilitative Officer, Resource Teacher and an onsite Psychologist. I will also be present as a supervisor when Loretta interviews our students.

Thank you for taking the time to review this letter. If you have any further questions please contact me.

Kind Regards,

Roslin Treacy

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